INTERNATIONAL SPINAL CORD INJURY DATA SET
BOWEL FUNCTION BASIC DATA SET (Version 1.1)

The Bowel Function Basic Spinal Cord Injury Data Set was developed by Klaus Krogh, Inder Perkash, Steven A Stiens and Fin Biering-Sørensen (see Krogh K et al. International bowel function basic spinal cord injury data set. Spinal Cord 2009;47:230-4 (Version 1.0)). For the terminology of the International Spinal Cord Injury Data Sets cf. Biering-Sørensen et al. The International Spinal Cord Injury Data Sets. Spinal Cord 2006;44(9):530-4.

Changes from Version 1.0 to Version 1.1:
In the Data Form the item "Frequency of fecal incontinence" has been slightly changed. The option "Not every week but at least once per month" has been changed to "Not every week but more than once per month". In addition in the Data Form "Enema (≥ 150 mL)" has been changed to "Enema (> 150 mL)".

Acknowledgements
Coloplast A/S, Denmark supported the work with this Data Set with an unconditional grant. We are thankful for comments and suggestions to the Bowel Function Basic Spinal Cord Injury Data Set received from Susan Charlifue, Lawrence C. Vogel, Dan Lammertse, William Donovan, Inge Eriks Hoogland, Karen Smith and Peter Christensen. We thank Vanessa Noonan for her help in the endorsement process.

Organisations that have endorsed the Bowel Function Basic Spinal Cord Injury Data Set as of September, 2009
International Spinal Cord Society
American Spinal Injury Association

Using the Bowel Function Basic Spinal Cord Injury Data Set
It is advised to practice with the training cases before implementing the Bowel Function Basic Spinal Cord Injury Data Set .
Try first to fill in a blank scoring sheet (see the Bowel Function Basic Spinal Cord Injury Data Set Collection Form), and afterwards check with the filled in scoring-sheet to see if the scoring has been done correctly.
The documentation with explanations for the Bowel Function Basic Spinal Cord Injury Data Set is found in the Introduction to the Bowel Function Basic Spinal Cord Injury Data Set.

The training cases have been contributed by Pia M Faaborg, Peter Christensen, Klaus Krogh and Fin Biering-Sørensen. The training cases were proof read by Ahmit Jha.

Questions and suggestions regarding the Bowel Function Basic Spinal Cord Injury Data Set should be directed to Klaus Krogh: klaukrog@rm.dk, Vanessa Noonan: Vanessa.Noonan@vch.ca, or Fin Biering-Sørensen: finbs@rh.dk.

INTERNATIONAL SPINAL CORD INJURY DATA SETS

BOWEL FUNCTION BASIC DATA SET (Version 1.1) – DATA FORM

Date performed: YYYYMMDD Unknown

Gastrointestinal or anal sphincter dysfunction unrelated to the spinal cord lesion:

□ No □ Yes, specify_____ □ Unknown

Surgical procedures on the gastrointestinal tract:

No
Appendicectomy, date performed YYYYMMDD
Cholecystectomy, date performed YYYYMMDD
Colostomy, date last performed YYYYMMDD
Ileostomy, date last performed YYYYMMDD
Other, specify: _____, date last performed YYYYMMDD
Unknown

Awareness of the need to defecate (within the last four weeks):

Normal (direct)
Indirect (For example: Abdominal cramping or discomfort - Abdominal muscle spasms - Spasms of lower extremities - Perspiration – Piloerection - Headache - Chills)
None
Unknown

Defecation method and bowel care procedures (within the last four weeks):

	Main	Supplementary
Normal defecation	□	□
Straining / bearing down to empty	□	□
Digital ano-rectal stimulation	□	□
Suppositories	□	□
Digital evacuation	□	□
Mini enema (Clysma ≤ 150 mL)	□	□
Enema (> 150 mL)	□	□
Colostomy	□	
Sacral anterior root stimulation	□	□
Other method, specify_____	□	□

□ Unknown

Average time required for defecation (within the last four weeks):

0-5 minutes 6-10 minutes 11-20 minutes 21-30 minutes
31-60 minutes More than 60 minutes Unknown

Frequency of defecation (within the last four weeks):

Three times or more per day Twice daily Once daily

Not daily but more than twice every week
Twice every week Once every week
Less than once every week, but at least once within the last four weeks
No defecation within the last four weeks
Not applicable Unknown

Frequency of fecal incontinence (within the last three months):
Two or more episodes per day One episode per day
Not every day but at least once per week
Not every week but more than once per month
Once every month Less than once per month Never
Unknown

Need to wear pad or plug (within the last three months):
Daily use Not every day but at least once per week
Not every week but at least once per month
Less than once per month Never
Unknown

Medication affecting bowel function / constipating agents (within the last four weeks):
No Yes, anticholinergics
Yes, narcotics
Yes, other, specify: _____
Unknown

Oral laxatives (within the last four weeks):
No Yes, osmotic laxatives (drops)
Yes, osmotic or bulking laxatives (tablets or granulates)
Yes, irritant laxatives (drops)
Yes, irritant laxatives (tablets)
Yes, prokinetics
Yes, other, specify:_____
Unknown

Perianal problems (within the last year):
None Haemorrhoids Perianal sores Fissures Rectal prolapse
Other, specify_____ Unknown

INTERNATIONAL SPINAL CORD INJURY DATA SETS

BOWEL FUNCTION BASIC DATA SET (Version 1.1) – COMMENTS

The working-group consists of:
Klaus Krogh
Steven Stiens
Inder Perkash
Fin Biering-Sørensen

The majority of individuals with spinal cord injury (SCI) have neurogenic bowel dysfunction including constipation, fecal incontinence and abdominal pain or discomfort (Stone JM et al. 1990, Glickmann S and Kamm MA 1996, Krogh K et al. 1997, Finnerup NB et al. 2008). Constipation related symptoms become significantly more severe with time since injury (Stone JM et al. 1990, Faaborg PM et al. 2007).

In accordance with the aims of the International Spinal Cord Injury Data Sets (Biering-Sørensen F et al. 2006) the aim of the Bowel Function Basic Data Set for Spinal Cord Injury is to standardize the collection and reporting of a minimal amount of information on bowel function in daily practice. Furthermore, the Bowel Function Basic Data Set makes it possible to evaluate and compare results from various published studies on bowel dysfunction after SCI.

The Bowel Function Basic Data Set is applicable to adult individuals with traumatic or non-traumatic supraconal, conal or cauda equina lesions. To ensure that data are collected in a uniform manner each variable and each response category within variables have been specifically defined.

The Bowel Function Basic Data Set will mostly be used in connection with the background information within the International SCI Core Data Set (DeVivo et al. 2006). For research purposes it is recommended that the Bowel Function Basic Data Set is used in connection with the Bowel Function Extended Data Set.

Several scores for fecal incontinence and constipation exist but none have yet been generally accepted for use in individuals with SCI. Information necessary for computation of the Skt. Marks score (Vaizey CJ et al. 1999) and the Wexner score (Jorge JMN et al. 1993) for fecal incontinence, the Cleveland Constipation Score (Agachan F et al. 1996), and the Neurogenic Bowel Dysfunction Score (Krogh K et al. 2006) is found within the combined Bowel Function Basic and Extended Data Sets.

References:

Agachan F, Chen T, Pfeiffer J, Reisman P, Wexner SD. A constipation scoring system to simplify evaluation and management of constipated patients. Dis Colon Rectum 1996; 39: 681-685.

Biering-Sørensen F, Charlifue S, DeVivo M, Noonan V, Post M, Stripling T, Wing P. International spinal cord injury data sets. Spinal Cord 2006; 44: 530-534.

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Drossman DA, Sandler RS, McKee DC, Lovitz AJ. Bowel patterns among subjects not seeking health care. Gastroenerology 1982; 83: 529-534.

Faaborg PM, Christensen P, Finnerup N, Laurberg S, Krogh K. The patern of colorectal dysfunction changes with time since spinal cord injury. Spinal Cord 2008; 46: 234-238.

Finnerup NB, Faaborg P, Krogh K, Jensen TS. Abdominal pain in long-term spinal cord injury. Spinal Cord 2008; 46: 198-203.

Glickmann S, Kamm MA. Bowel dysfunction in spinal cord injury patients. Lancet 1996; 347: 1651-1653.

Jones R, Lydeard S. Irritable bowel syndrome in the general population. Br Med J 1992; 304: 87-90.

Jorge JMN, Wexner SD. Etiology and management of faecal incontinence. Dis Colon Rectum 1993; 36: 77-97.

Krogh K, Nielsen J, Djurhuus JC, Mosdal C, Sabroe S, Laurberg S. Colorectal function in patients with spinal cord lesions. Dis Colon Rectum 1997; 40: 1233-1239.

Krogh K, Christensen P, Sabroe S, Laurberg S. Neurogenic bowel dysfunction score. Spinal Cord 2006; 44: 625

Stone JM, Nino-Murcia M, Wolfe VA, Perkash I. Chronic gastrointestinal problems in spinal cord injury aptients: a prospective analysis. Am J Gastroenterol 1990; 84: 1114-1119.

Vaizey CJ, Carapeti E, Cahill JA, Kamm MA. Prospective comparison of faecal incontinence grading systems. Gut 1999; 44: 77-80.

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VARIABLE NAME: Date of data collection

DESCRIPTION: This variable documents the date of data collection

CODES: YYYYMMDD

COMMENTS: As the collection of data on bowel function may be carried out at any time since SCI, the date of data collection is imperative to compute time since injury and to identify the data collected in relation to other data collected on the same individual at various time points.

VARIABLE NAME: Gastrointestinal or anal sphincter dysfunction unrelated to SCI

DESCRIPTION: This variable documents any gastrointestinal or anal sphincter dysfunction unrelated to SCI

CODES:
No
Yes, specify_____
Unknown

COMMENTS: This is gastrointestinal or anal sphincter dysfunction concomitant and thus unrelated to changes in bowel function due SCI.
Functional gastrointestinal disorders, especially irritable bowel syndrome and idiopathic constipation, are very common in the general population. The prevalence depends on the exact definitions used but vary from 5% up to approximately 20% (Jones R and Lydeard S 1992). The presence of functional or other gastrointestinal disorders before SCI may affect symptoms and treatment outcome.
Anal sphincter lesions due to childbirth are common and may contribute to fecal incontinence.
Many types of gastrointestinal and anal sphincter dysfunction exist and it is therefore impractical to give an exact list of such conditions.

VARIABLE NAME: Surgical procedures on the gastrointestinal tract

DESCRIPTION: This variable documents any surgical procedures on the gastrointestinal tract

CODES:
No
Appendicectomy, date performed YYYYMMDD
Cholecystectomy, date performed YYYYMMDD
Colostomy, date last performed YYYYMMDD
Ileostomy, date last performed YYYYMMDD
Other, specify: _____, date last performed YYYYMMDD
Unknown

COMMENTS: For the overall assessment of bowel function in individuals with SCI information about surgical procedures on the gastrointestinal tract is important. This variable covers any surgical procedure on the gastrointestinal tract before or after SCI. It also includes perianal surgery. Due to the large number of possible surgical procedures it is impractical to list more than the most important or common. Other surgical procedures on the gastrointestinal tract should be listed and specified under Other.

VARIABLE NAME: Awareness of the need to defecate (within the last four weeks)

DESCRIPTION: This variable documents any awareness of the need to defecate within the last four weeks

CODES:
Normal (direct)
Indirect (For example: Abdominal cramping or discomfort, abdominal muscle spasms, spasms of lower extremities, perspiration, piloerection, headache or chills)
None
Unknown

COMMENTS: Many individuals with SCI lack any awareness of the need to defecate. Others have indirect symptoms. These are mainly abdominal cramping or discomfort and spasms of the abdominal muscles or lower extremities. Autonomic symptoms including headache, perspiration, piloerection, and chills before or during defecation are common, especially in individuals with lesions above Th6 (Krogh et al. 1997). Autonomic symptoms are often unpleasant to the individual and may indicate insufficient bowel emptying. Lack of awareness of the need to defecate is especially common in individual with complete lesions and increases the risk of fecal incontinence. Symptoms may change with time and in the present data set they are given for the last four weeks.

VARIABLE NAME: Defecation method and bowel care procedures (within the last four weeks)

DESCRIPTION: This variable documents defecation method and bowel care procedures within the last four weeks

CODES:
Normal defecation – Main method
Normal defecation - Supplementary method
Straining / bearing down to empty – Main method
Straining / bearing down to empty - Supplementary method
Digital ano-rectal stimulation – Main method
Digital ano-rectal stimulation - Supplementary method
Suppositories – Main method
Suppositories - Supplementary method
Digital evacuation – Main method
Digital evacuation - Supplementary method
Mini enema (Clysma, $\leq$ 150 mL) – Main method
Mini enema (Clysma, $\leq$ 150 mL) - Supplementary method
Enema (>150 mL) – Main method
Enema (>150 mL) - Supplementary method
Colostomy
Sacral anterior root stimulation – Main method
Sacral anterior root stimulation - Supplementary method
Other – Main method, Specify: _____
Other - Supplementary method, Specify: _____
Unknown

COMMENTS: Individuals with SCI may use a combination of bowel emptying procedures. For practical purposes one should be defined as the Main method. Supplementary methods should be performed at least once every week. More than one supplementary method can be used. The choice of defecation method and bowel care procedures may change with time and in the present data set they are given for the last four weeks.
Digital ano-rectal stimulation is digital triggering of rectal contractions and anal relaxation and thus rectal emptying. Digital evacuation is the need to dig out stools with a finger. Mini enema (or Clysma) contains 150 ml or less and enema contain > 150 ml.
In individuals having a colostomy, this is always considered the main method for defecation.

VARIABLE NAME: Average time required for defecation (within the last four weeks)

DESCRIPTION: This variable documents average time required for each defecation within the last four weeks

CODES:
0-5 minutes
6-10 minutes
11-20 minutes
21-30 minutes
31-60 minutes
More than 60 minutes
Not applicable
Unknown

COMMENTS: Time needed for defecation is clinically very important and strongly associated with impact on quality of life (Krogh et al. 2006). The time given is from first transferring to the toilet or commode until end of defecation and transferal to wheel chair or moving from the toilet. If bladder emptying, body washing, shaving etc is also performed while sitting at the toilet time for this is subtracted. For individuals performing bowel management while lying in the bed time required is from beginning to end of bowel management not including time for bladder management, body washing etc. Time needed for defecation is the assessed average time for *each* defecation within the last four weeks.

VARIABLE NAME: Frequency of defecation (within the last four weeks)

DESCRIPTION: This variable documents the average frequency of defecation within the last four weeks

CODES:
Three times or more per *day*
Twice *daily*
Once *daily*
Not daily but more than twice every week
Twice every week
Once every *week*
Less than once every week but at least once within the last four weeks
No defecation within the last four weeks
Not applicable
Unknown

COMMENTS: The frequency of defecation is very variable. However, in the general population more than 94% defecate between three times per day and three times per week (Drossman et al. 1982). Among individuals with SCI approximately 3% defecate less

	than once every week. Extremely few individuals will not have defecated within the last four weeks. However, in order to be able to compute the Cleveland Constipation Score this option is included. Infrequent defecation is an indicator of insufficient bowel management and associated with impact on quality of life (Krogh et al. 2006). This variable does not distinguish between spontaneous or assisted defecation. Not applicable can be used i.e. in subjects with ileo- or colostomy.

VARIABLE NAME:	Frequency of fecal incontinence (within the last three months)
DESCRIPTION:	This variable documents the average frequency of incontinence to *solid or liquid* stools within the last three months
CODES:	Two or more episodes per day One episode per day Not every day but at least once per week Not every week but more than once per month Once per month Less than once per month Never Unknown
COMMENTS:	Fecal incontinence is defined as involuntary passage of stools. It has profound influence on quality of life and may cause severe restriction on social activities. The frequency of fecal incontinence is variable even within subjects, so it is assessed over a period of three months. This variable does not distinguish between incontinence to *solid or liquid* stools. In subjects with ileo- or colostomy leakage is considered as fecal incontinence.

VARIABLE NAME:	Need to wear pad or plug (within the last three months)
DESCRIPTION:	This variable documents the need to wear a pad or plug within the last three months
CODES:	Daily use Not every day but at least once per week Not every week but at least once per month Less than once per month Never Unknown
COMMENTS:	This variable describes the need to wear a pad due to fecal incontinence or combined fecal and urinary incontinence. The need to wear a pad only for urinary incontinence is not included.

	The need to wear a pad indicates insufficient bowel management. The use of anal plug is mainly relevant for individuals with conal or cauda equina lesions.

VARIABLE NAME:	Medication affecting bowel function / constipating agents (within the last four weeks)
DESCRIPTION:	The variable documents medication affecting bowel function including constipating agents within the last four weeks
CODES:	No Yes, anticholinergics Yes, narcotics Yes, other, specify: _____ Unknown
COMMENTS:	A number of drugs affect gastrointestinal motility. The most commonly used among individuals with SCI are probably anticholinergics and narcotics. Other common examples are: calcium antagonists, diuretics, serotonin reuptake inhibitors, and spasmolytics. Many drugs affect gastrointestinal function and it is impractical to give an exact list of them all. It does not only include orally taken agents but also patches, suppositories and injections. It does not include laxatives. Constipating agents, especially loperamide, taken by a minority of individuals with SCI against fecal incontinence should also be listed here.

VARIABLE NAME:	Oral laxatives (within the last four weeks)
DESCRIPTION:	The variable documents the use of oral laxatives within the last four weeks
CODES:	No Yes, osmotic laxatives (drops) Yes, osmotic or bulking laxatives (tablets or granulates) Yes, irritant laxatives (drops) Yes, irritant laxatives (tablets) Yes, prokinetics Yes, other, specify:_____ Unknown
COMMENTS:	Oral laxatives are commonly used by individuals with SCI. A large number of oral laxatives exist either as drops or tablets and it is impractical to give a full list within the frames of this data set. Commonly used bulking or osmotic agents are lactulose, psyllium, magnesium and sorbitol. Commonly used irritant

laxatives are bisacodyl and sodium picosulphate. Cisapride, previously the most commonly used oral prokinetic agent, is now withdrawn from common use and is rarely used in persons with SCI.

VARIABLE NAME: Perianal problems (within the last year)

DESCRIPTION: This variable documents the presence of perianal problems within the last year

CODES:
None
Haemorrhoids
Perianal sores
Fissures
Rectal prolapse
Other, specify_____
Unknown

COMMENTS: Due to staining and assisted defecation haemorrhoids, fissures, and rectal prolapse are more common among individuals with SCI than in the general population. Anal soiling may contribute to perianal sores. In the present data set perianal sores are located within the crena ani or the perineum and not on the buttocks or lower back. For practical purposes no distinction is made in the present data set between rectal mucosal prolapse and full-wall rectal prolapse.
Perianal problems may change with time and only those present within the last year should be noted.

CASES FOR TRAINING OF THE INTERNATIONAL BOWEL FUNCTION BASIC SPINAL CORD INJURY DATA SET

CASE 1 FOR BOWEL FUNCTION BASIC DATA SET TRAINING

A 28 years old male with motor and sensory complete spinal cord lesion at C7 came for his regular follow-up visit to the department June 12, 2009. The lesion was caused by a motorbike accident four years before. During the accident he had trauma to the abdomen. A laparotomy was performed followed by splenectomy. There was no history of other abdominal or perianal surgery. Before the accident he had normal bowel function with controlled defecation every morning. Since the accident, he describes that he has lost normal sensation for bowel movements. Instead, he usually gets chills and perspiration on the neck and left shoulder. He has a helper who performs digital anorectal stimulation of him each morning. The procedure takes 45 minutes and usually results in defecation. If there has not been any bowel movement for two days they use a mini enema (120 ml). This happens approximately every second week.

He has incontinence for liquid stools once or twice per month and for that reason he does not take any oral laxatives. Due to spasms in the legs he takes Baclofen R and due to pain in the shoulders he occasionally takes Paracetamol.

The condition has been stable over the last three years and he is now referred for training in transanal irrigation. At inspection the perineum is normal. At digital examination he is unable to feel the investigation. There is normal anal resting tone but no squeeze pressure.

INTERNATIONAL SPINAL CORD INJURY DATA SETS

BOWEL FUNCTION BASIC DATA SET (Version 1.1) – DATA FORM for CASE 1

Date performed: 20090612 Unknown

Gastrointestinal or anal sphincter dysfunction unrelated to the spinal cord lesion:

X No ☐ Yes, specify_____ ☐ Unknown

Surgical procedures on the gastrointestinal tract:

X No
Appendicectomy, date performed YYYYMMDD
Cholecystectomy, date performed YYYYMMDD
Colostomy, date last performed YYYYMMDD
Ileostomy, date last performed YYYYMMDD
Other, specify: _____, date last performed YYYYMMDD
Unknown

Awareness of the need to defecate (within the last four weeks):

Normal (direct)
X Indirect (For example: Abdominal cramping or discomfort - Abdominal muscle spasms - Spasms of lower extremities - Perspiration – Piloerection - Headache - Chills)
None
Unknown

Defecation method and bowel care procedures (within the last four weeks):

	Main	Supplementary
Normal defecation	☐	☐
Straining / bearing down to empty	☐	☐
Digital ano-rectal stimulation	X	☐
Suppositories	☐	☐
Digital evacuation	☐	☐
Mini enema (Clysma ≤ 150 mL)	☐	X
Enema (> 150 mL)	☐	☐
Colostomy	☐	
Sacral anterior root stimulation	☐	☐
Other method, specify_____	☐	☐

☐ Unknown

Average time required for defecation (within the last four weeks):

0-5 minutes 6-10 minutes 11-20 minutes 21-30 minutes
X 31-60 minutes More than 60 minutes Unknown

Frequency of defecation (within the last four weeks):

Three times or more per day Twice daily X Once daily

Not daily but more than twice every week
Twice every week Once every week
Less than once every week, but at least once within the last four weeks
No defecation within the last four weeks
Not applicable Unknown

Frequency of fecal incontinence (within the last three months):
Two or more episodes per day One episode per day
Not every day but at least once per week
X Not every week but more than once per month
Once every month Less than once per month Never
Unknown

Need to wear pad or plug (within the last three months):
Daily use Not every day but at least once per week
Not every week but at least once per month
Less than once per month X Never
Unknown

Medication affecting bowel function / constipating agents (within the last four weeks):
No Yes, anticholinergics
Yes, narcotics
X Yes, other, specify: Baclofen
Unknown

Oral laxatives (within the last four weeks):
X No Yes, osmotic laxatives (drops)
Yes, osmotic or bulking laxatives (tablets or granulates)
Yes, irritant laxatives (drops)
Yes, irritant laxatives (tablets)
Yes, prokinetics
Yes, other, specify:_____
Unknown

Perianal problems (within the last year):
X None Haemorrhoids Perianal sores Fissures Rectal prolapse
Other, specify_____ Unknown

CASE 2 FOR BOWEL FUNCTION BASIC DATA SET TRAINING

A 24 year old woman born with lumbosacral myelomeningocele came for consultation June 12, 2009. She has no hydrocephalus and is able to walk with crutches. An appendectomy was performed when she was eight years old (date of surgery: February 3th 1993). She does not follow any specific bowel regime. There is spontaneous defecation every day. This only takes 8-10 minutes. Even though she has what she finds must be normal sensation for defecation, she has very short time to reach the toilet and is incontinent to both liquid and solid stools. Some years ago she had fecal incontinence once or twice per month but now it is almost every day and she always needs to wear diapers. She does not take any medication.

At inspection there is prolapse of the rectal mucosa. At digital examination there is very low anal tone and only weak squeeze pressure. She can feel the investigation.

INTERNATIONAL SPINAL CORD INJURY DATA SETS

BOWEL FUNCTION BASIC DATA SET (Version 1.1) – DATA FORM for CASE 2

Date performed: 20090612 Unknown

Gastrointestinal or anal sphincter dysfunction unrelated to the spinal cord lesion:

☐ No ☐ Yes, specify_____ X Unknown

Surgical procedures on the gastrointestinal tract:

No X Appendicectomy, date performed 19930203
Cholecystectomy, date performed YYYYMMDD
Colostomy, date last performed YYYYMMDD
Ileostomy, date last performed YYYYMMDD
Other, specify: _____, date last performed YYYYMMDD
Unknown

Awareness of the need to defecate (within the last four weeks):

X Normal (direct)
Indirect (For example: Abdominal cramping or discomfort - Abdominal muscle spasms - Spasms of lower extremities - Perspiration – Piloerection - Headache - Chills)
None
Unknown

Defecation method and bowel care procedures (within the last four weeks):

	Main	Supplementary
Normal defecation	X	☐
Straining / bearing down to empty	☐	☐
Digital ano-rectal stimulation	☐	☐
Suppositories	☐	☐
Digital evacuation	☐	☐
Mini enema (Clysma ≤ 150 mL)	☐	☐
Enema (> 150 mL)	☐	☐
Colostomy	☐	
Sacral anterior root stimulation	☐	☐
Other method, specify_____	☐	☐

☐ Unknown

Average time required for defecation (within the last four weeks):

0-5 minutes X 6-10 minutes 11-20 minutes 21-30 minutes
31-60 minutes More than 60 minutes Unknown

Frequency of defecation (within the last four weeks):

Three times or more per day Twice daily X Once daily

Not daily but more than twice every week
Twice every week Once every week
Less than once every week, but at least once within the last four weeks
No defecation within the last four weeks
Not applicable Unknown

Frequency of fecal incontinence (within the last three months):
Two or more episodes per day One episode per day
X Not every day but at least once per week
Not every week but more than once per month
Once every month Less than once per month Never
Unknown

Need to wear pad or plug (within the last three months):
X Daily use Not every day but at least once per week
Not every week but at least once per month
Less than once per month Never
Unknown

Medication affecting bowel function / constipating agents (within the last four weeks):
X No Yes, anticholinergics
Yes, narcotics
Yes, other, specify: _____
Unknown

Oral laxatives (within the last four weeks):
X No Yes, osmotic laxatives (drops)
Yes, osmotic or bulking laxatives (tablets or granulates)
Yes, irritant laxatives (drops)
Yes, irritant laxatives (tablets)
Yes, prokinetics
Yes, other, specify:_____
Unknown

Perianal problems (within the last year):
None Haemorrhoids Perianal sores Fissures X Rectal prolapse
Other, specify_____ Unknown

CASE 3 FOR BOWEL FUNCTION BASIC DATA SET TRAINING

32 year old female, previously completely healthy, was on June 5th 1999 involved in a car accident, where she had an unstable fracture of T4. The fracture was stabilized at an acute operation. Afterwards, she was left with a motor complete and sensory incomplete spinal cord injury. She was rehabilitated and now she lives an almost independent life using a wheel chair. Due to bladder dysfunction she had a Mitrofanoff conduit to the bladder performed on the April 2th 2004. Initially, she had no natural call to stool and used peroral laxatives (Bisacodyl-tablets) and digital stimulation to initiate defecation every second day. However, bowel problems progressed with increased time spent at bowel management - sometimes 45 minutes and often with a feeling of incomplete evacuation. Furthermore, she had become incontinent to solid stool approximately twice per month. Therefore, she had started to use pads nearly every day. She had no perianal problems. She had continued to use Bisacodyl tablet, but did not use any other medication.

She was seen in the outpatient clinic on September 5th 2007 and described the pattern of supraconal neurogenic bowel dysfunction as presented above. She is now about to start transanal irrigation.

INTERNATIONAL SPINAL CORD INJURY DATA SETS

BOWEL FUNCTION BASIC DATA SET (Version 1.1) – DATA FORM for CASE 3

Date performed: 20070905 Unknown

Gastrointestinal or anal sphincter dysfunction unrelated to the spinal cord lesion:

X No ☐ Yes, specify_____ ☐ Unknown

Surgical procedures on the gastrointestinal tract:

No
Appendicectomy, date performed YYYYMMDD
Cholecystectomy, date performed YYYYMMDD
Colostomy, date last performed YYYYMMDD
Ileostomy, date last performed YYYYMMDD
X Other, specify: Mitrophanoff conduit to the bladder, date last performed 20040402
Unknown

Awareness of the need to defecate (within the last four weeks):

Normal (direct)
Indirect (For example: Abdominal cramping or discomfort - Abdominal muscle spasms - Spasms of lower extremities - Perspiration – Piloerection - Headache - Chills)
X None
Unknown

Defecation method and bowel care procedures (within the last four weeks):

	Main	Supplementary
Normal defecation	☐	☐
Straining / bearing down to empty	☐	☐
Digital ano-rectal stimulation	X	☐
Suppositories	☐	☐
Digital evacuation	☐	☐
Mini enema (Clysma ≤ 150 mL)	☐	☐
Enema (> 150 mL)	☐	☐
Colostomy	☐	
Sacral anterior root stimulation	☐	☐
Other method, specify_____	☐	☐

☐ Unknown

Average time required for defecation (within the last four weeks):

0-5 minutes 6-10 minutes 11-20 minutes 21-30 minutes
X 31-60 minutes More than 60 minutes Unknown

Frequency of defecation (within the last four weeks):

Three times or more per day Twice daily Once daily
X Not daily but more than twice every week

Twice every week Once every week
Less than once every week, but at least once within the last four weeks
No defecation within the last four weeks
Not applicable Unknown

Frequency of fecal incontinence (within the last three months):
Two or more episodes per day One episode per day
Not every day but at least once per week
X Not every week but more than once per month
Once every month Less than once per month Never
Unknown

Need to wear pad or plug (within the last three months):
Daily use X Not every day but at least once per week
Not every week but at least once per month
Less than once per month Never
Unknown

Medication affecting bowel function / constipating agents (within the last four weeks):
X No Yes, anticholinergics
Yes, narcotics
Yes, other, specify: _____
Unknown

Oral laxatives (within the last four weeks):
No Yes, osmotic laxatives (drops)
Yes, osmotic or bulking laxatives (tablets or granulates)
Yes, irritant laxatives (drops)
X Yes, irritant laxatives (tablets)
Yes, prokinetics
Yes, other, specify:_____
Unknown

Perianal problems (within the last year):
X None Haemorrhoids Perianal sores Fissures Rectal prolapse
Other, specify_____ Unknown

CASE 4 FOR BOWEL FUNCTION BASIC DATA SET TRAINING

A 49 year old female came for a follow-up on June 5th 2008. On January 20th 2002 she was involved in a car accident leaving her with a motor and sensory complete spinal cord injury at C5. She is the mother of two. When giving birth to her youngest child she had a complete anal external and internal sphincter rupture. Primary suture of the anal sphincter and perineum was performed the same day with a satisfactory outcome. However, as the years passed she had flatus incontinence and later urge and sometimes episodes of faecal incontinence for liquid stools. Since the accident she has become increasingly constipated. Initially, she was treating constipation with oral laxatives. However, she had faecal soiling nearly daily causing perianal sores. Transanal colonic irrigation was introduced in order to treat faecal impaction and reduce faecal incontinence. This was supplemented with the oral laxatives. Tranaanal irrigation was troublesome for her as she could not keep the irrigation fluid in the rectum long enough to treat faecal impaction. Therefore, an appendicostomy with a colostomy was performed on October 6th 2007. The irrigation is now performed by her helpers through the appendicostomy every other day, on average spending 30 minutes on the routine. This routine results in passing of the stools approximately three times a week, and she does not require laxatives anymore. She has no incontinence episodes, only little abdominal bloating and – for the last eight months - no perianal sores. She does not wear diapers or take medication affecting gastrointestinal function.

INTERNATIONAL SPINAL CORD INJURY DATA SETS

BOWEL FUNCTION BASIC DATA SET (Version 1.1) – DATA FORM for CASE 4

Date performed: 20080605 Unknown

Gastrointestinal or anal sphincter dysfunction unrelated to the spinal cord lesion:

☐ No X Yes, specify__flatus and faecal incontinence _____
☐ Unknown

Surgical procedures on the gastrointestinal tract:

No
Appendicectomy, date performed YYYYMMDD
Cholecystectomy, date performed YYYYMMDD
X Colostomy, date last performed 20071006
Ileostomy, date last performed YYYYMMDD
X Other, specify: _appendicostomy_, date last performed 20071006
Unknown

Awareness of the need to defecate (within the last four weeks):

Normal (direct)
Indirect (For example: Abdominal cramping or discomfort - Abdominal muscle spasms - Spasms of lower extremities - Perspiration – Piloerection - Headache - Chills)
X None
Unknown

Defecation method and bowel care procedures (within the last four weeks):

	Main	Supplementary
Normal defecation	☐	☐
Straining / bearing down to empty	☐	☐
Digital ano-rectal stimulation	☐	☐
Suppositories	☐	☐
Digital evacuation	☐	☐
Mini enema (Clysma ≤ 150 mL)	☐	☐
Enema (> 150 mL)	☐	☐
Colostomy	X	
Sacral anterior root stimulation	☐	☐
Other method, specify_irrigation through the appendicostomy__	☐	X

☐ Unknown

Average time required for defecation (within the last four weeks):

0-5 minutes 6-10 minutes 11-20 minutes X 21-30 minutes
31-60 minutes More than 60 minutes Unknown

Frequency of defecation (within the last four weeks):

Three times or more per day Twice daily Once daily

X Not daily but more than twice every week
Twice every week Once every week
Less than once every week, but at least once within the last four weeks
No defecation within the last four weeks
Not applicable Unknown

Frequency of fecal incontinence (within the last three months):
Two or more episodes per day One episode per day
Not every day but at least once per week
Not every week but more than once per month
Once every month Less than once per month X Never
Unknown

Need to wear pad or plug (within the last three months):
Daily use Not every day but at least once per week
Not every week but at least once per month
Less than once per month X Never
Unknown

Medication affecting bowel function / constipating agents (within the last four weeks):
X No Yes, anticholinergics
Yes, narcotics
Yes, other, specify: _____
Unknown

Oral laxatives (within the last four weeks):
X No Yes, osmotic laxatives (drops)
Yes, osmotic or bulking laxatives (tablets or granulates)
Yes, irritant laxatives (drops)
Yes, irritant laxatives (tablets)
Yes, prokinetics
Yes, other, specify:_____
Unknown

Perianal problems (within the last year):
X None Haemorrhoids Perianal sores Fissures Rectal prolapse
Other, specify_____ Unknown

CASE 5 FOR BOWEL FUNCTION BASIC DATA SET TRAINING

One year after sustaining an incomplete spinal cord injury to the second and third lumbar vertebra a young man sought medical advice for daily episodes of fecal incontinence. He is 23 years old and the problem is causing him increasingly psychological suffering as he is now dating a very nice girl. Several times a week he has to change plans for dates or meetings and reports major impact on quality of life. He lives in a wheelchair accessible flat and manages all aspects of life independently. He takes no medication.

Before the accident he was healthy and had no past medical problems. Today, February 1st 2009, the status of his bowel dysfunction is: No call for defecation and therefore no ability to defer defecation at all. This leads to several daily episodes of faecal incontinence and need for diapers. Mostly, his stools are liquid, but sometimes every month he is suffering from incontinence episodes even though his faeces are solid. Shortly after the incident he suffered from painful sores around the anus but this has posed no problem for him the recent six months. He is not reporting any flatus incontinence. Medical treatment used to include small enemas and suppositories with insufficient effect and treatment was terminated three months ago. Each morning he digitally stimulates defecation sitting on the raised toilet seat - on average spending ten minutes on the routine. This is also his preferred place for changing diapers and cleaning himself after incontinence episodes.

INTERNATIONAL SPINAL CORD INJURY DATA SETS

BOWEL FUNCTION BASIC DATA SET (Version 1.1) – DATA FORM for CASE 5

Date performed: 20090201 Unknown

Gastrointestinal or anal sphincter dysfunction unrelated to the spinal cord lesion:

X No □ Yes, specify_____ □ Unknown

Surgical procedures on the gastrointestinal tract:

X No Appendicectomy, date performed YYYYMMDD
Cholecystectomy, date performed YYYYMMDD
Colostomy, date last performed YYYYMMDD
Ileostomy, date last performed YYYYMMDD
Other, specify: _____, date last performed YYYYMMDD
Unknown

Awareness of the need to defecate (within the last four weeks):

Normal (direct)
Indirect (For example: Abdominal cramping or discomfort - Abdominal muscle spasms - Spasms of lower extremities - Perspiration – Piloerection - Headache - Chills)
X None
Unknown

Defecation method and bowel care procedures (within the last four weeks):

	Main	Supplementary
Normal defecation	□	□
Straining / bearing down to empty	□	□
Digital ano-rectal stimulation	X	□
Suppositories	□	□
Digital evacuation	□	□
Mini enema (Clysma ≤ 150 mL)	□	□
Enema (> 150 mL)	□	□
Colostomy	□	
Sacral anterior root stimulation	□	□
Other method, specify_____	□	□

□ Unknown

Average time required for defecation (within the last four weeks):

0-5 minutes X 6-10 minutes 11-20 minutes 21-30 minutes
31-60 minutes More than 60 minutes Unknown

Frequency of defecation (within the last four weeks):

X Three times or more per day Twice daily Once daily

Not daily but more than twice every week
Twice every week Once every week
Less than once every week, but at least once within the last four weeks
No defecation within the last four weeks
Not applicable Unknown

Frequency of fecal incontinence (within the last three months):
X Two or more episodes per day One episode per day
Not every day but at least once per week
Not every week but more than once per month
Once every month Less than once per month Never
Unknown

Need to wear pad or plug (within the last three months):
X Daily use Not every day but at least once per week
Not every week but at least once per month
Less than once per month Never
Unknown

Medication affecting bowel function / constipating agents (within the last four weeks):
X No Yes, anticholinergics
Yes, narcotics
Yes, other, specify: _____
Unknown

Oral laxatives (within the last four weeks):
X No Yes, osmotic laxatives (drops)
Yes, osmotic or bulking laxatives (tablets or granulates)
Yes, irritant laxatives (drops)
Yes, irritant laxatives (tablets)
Yes, prokinetics
Yes, other, specify:_____
Unknown

Perianal problems (within the last year):
None Haemorrhoids X Perianal sores Fissures Rectal prolapse
Other, specify_____ Unknown